

University of Groningen

Unpacking community mobility

Nanninga, Christa S; Meijering, Louise; Postema, Klaas; Schonherr, Marleen C; Lettinga, Ant
T

Published in:
Disability and Rehabilitation

DOI:
[10.1080/09638288.2017.1323031](https://doi.org/10.1080/09638288.2017.1323031)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2018

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Nanninga, C. S., Meijering, L., Postema, K., Schonherr, M. C., & Lettinga, A. T. (2018). Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors. *Disability and Rehabilitation*, 40(17), 2015-2024. <https://doi.org/10.1080/09638288.2017.1323031>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.



Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors

Christa S. Nanninga, Louise Meijering, Klaas Postema, Marleen C. Schönherr & Ant T. Lettinga

To cite this article: Christa S. Nanninga, Louise Meijering, Klaas Postema, Marleen C. Schönherr & Ant T. Lettinga (2018) Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors, *Disability and Rehabilitation*, 40:17, 2015-2024, DOI: [10.1080/09638288.2017.1323031](https://doi.org/10.1080/09638288.2017.1323031)

To link to this article: <https://doi.org/10.1080/09638288.2017.1323031>



© 2017 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 17 May 2017.



[Submit your article to this journal](#)



Article views: 426



[View related articles](#)



[View Crossmark data](#)



Citing articles: 1 [View citing articles](#)

RESEARCH PAPER



Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors

Christa S. Nanninga^a, Louise Meijering^b, Klaas Postema^c, Marleen C. Schönherr^d and Ant T. Lettinga^a

^aCenter for Rehabilitation, University Medical Center Groningen, University of Groningen, Haren, The Netherlands; ^bPopulation Research Centre, Urban and Regional Studies Institute, Faculty of Spatial Sciences, University of Groningen, Groningen, The Netherlands; ^cDepartment of Rehabilitation Medicine, Center for Rehabilitation, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands; ^dDepartment of Rehabilitation Medicine, Center for Rehabilitation, University Medical Center Groningen, University of Groningen, Haren, The Netherlands

ABSTRACT

Purpose: To enrich the discussion on mobility in stroke rehabilitation by translating theoretical repertoires of mobility from the context of geography to rehabilitation.

Method: Qualitative research methodology was applied, and included in-depth interviews with stroke survivors.

Results: This study revealed: (a) social and material differences in clinical, private and public places; (b) ambivalences and shifting tensions in bodily, family and community life; (c) differences in access to resources to be used for mobility. Moving around safely was not a matter of being physically able to walk independently, it also involved dealing with different human actors – such as children, partners and shoppers, and non-human actors – such as doorbells and traffic rules. Stroke survivors had to balance exercise and training, family and working life, and leisure and pleasure, and to renegotiate their mobility in each context.

Conclusions: Our study showed that mobility has many aspects that interact with each other in multiple ways for stroke survivors when they return home and thereafter. The current focus on adherence to mobility and exercise training at home needs to be critically reviewed as it does not capture the multiplicities embodied in real-life settings.

ARTICLE HISTORY

Received 28 December 2015
Revised 14 April 2017
Accepted 21 April 2017

KEYWORDS

Mobility; community ambulation; participation; stroke; geography; qualitative research

► IMPLICATIONS FOR REHABILITATION

- Rehabilitation medicine needs to consider mobility as a way to connect places that are meaningful to individuals rather than as movements from A to B.
- Clinical outcome measurement tools, such as the 10-meter walk test, are inadequate for evaluating participation in the mobility domain at home or in the community.
- Mobility issues at the participation domain need to be considered in “how they hang together” rather than distinguished in different disciplinary domains.
- Rehabilitation practitioners should teach stroke survivors concrete strategies on how to creatively deal with the ambivalences and tensions around mobility in home and community life.

Introduction

Improving mobility is a primary goal in stroke rehabilitation [1,2]. The International Classification of Functioning, Disability, and Health (ICF) defines mobility as “moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running or climbing, and by using various forms of transportation” [3]. Beneficial effects in improving the mobility of stroke survivors have been recorded for fitness training, high-intensity therapy and repetitive task training in specialist multidisciplinary stroke units [4]. However, despite good mobility outcomes in stroke units, it remains a challenge to translate the improvements made in the clinic into enhanced participation in community ambulation [5,6]. On returning home, stroke survivors often experience loss of independence in activities of daily living and restricted community ambulation, which in turn limits their ability to engage in work, leisure and community events, often with devastating

consequences for family caregivers [7,8]. This illustrates the importance of a more detailed study of mobility following stroke, specifically in the participation domain [9,10].

As individuals with chronic stroke are vulnerable to the effects of a sedentary lifestyle, adherence to fitness and exercise training after inpatient rehabilitation is strongly promoted [11–16]. Community ambulation interventions are also applied to prevent mobility decline in individuals with chronic stroke, consisting of walking practice in a variety of settings in the community, an indoor activity that mimics community walking (including virtual reality and mental imagery) [8,17,18]. Current evidence shows that interventions including behaviour change techniques tend to be more effective in improving real world walking habits than exercise alone [18]. However, there is insufficient evidence to establish the effect of fitness or community ambulation interventions in improving the community mobility of stroke survivors in their own living environments [8,17].

CONTACT Christa S. Nanninga ✉ c.s.nanninga@umcg.nl 📮 Diltgweg 5, PO Box 30002, 9750 RA Haren, The Netherlands

© 2017 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

Mobility training is assessed and evaluated in rehabilitation medicine using validated measurement tools that range from simple scales of timed tests, the examination of gait, balance, posture and independence to portable ambulatory activity monitors and complex laboratory-bound equipment that measures physical force, movements and physiological markers (e.g., heart rate and oxygen uptake) [5,15,19]. Self-reported measures including survey questionnaires and diary entries are also used [6,19,20]. According to Lord and Rochester [5], this way of defining and measuring mobility in clinical and laboratory settings does not capture the full complexity of the concept and its meaning in stroke survivors' own living environments. A better theoretical understanding of community mobility is therefore critical when designing therapeutic strategies that maximize participation and minimize disability [5,9]. Gardner [9] describes community mobility as a process that is complex, dynamic and often difficult, since it is challenged by a myriad of individual and environmental factors that change from one day to the next. Therefore, it is important to also study the knowledge that stroke survivors develop about mobility in their daily lives, and make this practical patient knowledge transferable and useful to others, or "turn it into science" [21, p. 1].

In this article, we aim to enrich the discussion on mobility in stroke rehabilitation by articulating the practical knowledge of stroke survivors about their (im)mobilities, at the places where they wish to (inter)act. To achieve this aim, we draw on care research that unravels and articulates details to do with care, to strengthen care practices, and whoever is involved in them [21–23]. Our assumption is that the articulated practical knowledge of patients may help to improve the knowledge practices of therapists and researchers. For that purpose, we delved into the embodied mobility practices of stroke survivors in the clinic, at home and in the community, as part of a broader qualitative study on home- and place-making with stroke survivors who were discharged after inpatient rehabilitation in a Dutch rehabilitation stroke unit [7]. To open up new ways of understanding mobility we translated theoretical repertoires of mobility from the context of the social sciences and geography to rehabilitation. In the next section, we will take the reader on a condensed tour of the social science literature, geography in particular, on mobility [24–27].

The mobility turn in the social sciences

In the social sciences, mobility has long been understood as movements from one place to another, which is quite similar to how it is currently conceptualized in the ICF and related rehabilitation literature. In the 1990s, with the worldwide increase in mobility (globalization) and emerging virtual forms of mobility, ideas on mobility began to change; this has been labeled the "mobility turn" in the social sciences [24]. Sheller and Urry [24] described mobility as "the importance of the systematic movements of people for work and family life, for leisure and pleasure, and for politics and protest" (p. 208). This resembles the way stroke rehabilitation defines community ambulation, albeit on a smaller scale: mobility inside and outside the home "to encompass activities such as visits to the supermarket, shopping mall, and bank; social outings; vacations, and pursuit of leisure activities" [10]. In the social sciences, however, there is also a political dimension to mobility on a larger scale [24,26]. For instance, international travel is associated with both elite, high-skilled migrants and undocumented migrants, each revealing very different mobility resources. Depending on resources, such as financial means, time and abilities, different people thus have different access to mobility.

Cresswell [25,26] divided the concept of mobility into three analytical dimensions: physical movement, representations and

practices. Physical movement is about actual movement from one place to another. Representations of movement give it its shared meaning. The practice of movement encompasses mobility as experienced and embodied in everyday activities [25,26]. The dimension of mobility practices is particularly important in the context of our study, as it shifts the focus to everyday mobilities and to the spatial scale of the body. The practices dimension also directs attention to the movement of people, things and ideas. Moreover, it expresses the idea that human and non-human actors may enable or hinder each other [24]. The concept of mobility practices therefore allows for a better understanding of mobility in terms of the specific physical and mental opportunities and human and non-human "obstacles" that both enable and disable the mobility of stroke survivors in everyday activities. This also implies that there is not one "mobility", but rather that mobilities such as driving, virtual travel, letter writing, flying and walking need to be understood in their fluid interdependence, and as being situated in different socio-spatial contexts [24–26].

Further work on mobility that is relevant for stroke survivors has focused on the mobility of older adults [28,29]. Especially relevant there is the concept of the "mobility of the self" or the idea that mobility is also related to a general will to connect with and be part of the world [27]. As stroke survivors become impaired in their capacity to move, both physically and cognitively, they may also lose this ability or general will to connect with the outside world [7].

Our theoretical study on the "mobility turn" allowed us to study the practical knowledge of stroke survivors in home and community life through a human geographical lens. Human geography "is centrally concerned with the ways in which place, space and environment are both the condition and in part the consequence of human activities." [30, p. 350]. In this context, mobility is considered as a way to connect places that are meaningful to individuals rather than as movements from A to B. Such a perspective has the potential to uncover the challenges and shifting tensions in bodily, family and community life of stroke survivors. This requires stroke survivors' attention and tinkering upon getting back to everyday life after inpatient rehabilitation. Tinkering as well as doctoring are concepts that have been developed in ethnographic research to give words to the specificities of care and clinical practices in contrast to the linear way of working established in clinical epidemiological research [22].

Methods

Design

The design of this study is interdisciplinary of character. It moves theoretical repertoires – that are developed in spatial sciences after the mobility turn – to the field of stroke rehabilitation, with the aim to articulate silent layers and issues that deserve concern and attention in rehabilitation practice and science. The concept of "embodied mobility practices" needs to be understood as being situated in different socio-spatial contexts. Moreover, it enabled us to study mobility as a set of materially heterogeneous practices through which meaningful places are connected, rather than as an individual's ability to move from A to B. This bears a resemblance to the material semiotic work of ethnographers who aim to improve and strengthen care practices by articulating their specificities, by drawing contrasts, and giving words to events that have been previously unspoken. In so doing, they also seek to rethink and frame care and technology by analyzing them together [22,31]. We drew on this ethnographic approach, and directed our attention to the (im)mobilities practiced by stroke

survivors in the clinic, at home and in the community, focusing on differences and similarities between places.

Participants

The study participants were 33 stroke survivors with moderate to severe stroke who received or had received multidisciplinary treatment in a rehabilitation stroke unit. The characteristics of the stroke survivors are summarized in Table 1. Each participant took part voluntarily and provided informed consent. The Medical Ethical Review Committee of the University Medical Center Groningen exempted this study from the review process.

Setting

All participants had been admitted to a rehabilitation stroke unit in the Netherlands after being discharged from an acute stroke unit at a hospital. So, this local service meets the four criteria set out for a rehabilitation stroke unit: (a) there was a multidisciplinary team that provides stroke care at a dedicated ward; (b) the stroke team, including nursing staff, is specialized and trained in stroke rehabilitation; (c) routine involvement of caregivers in the rehabilitation process is established in the form of partner groups; and (d) new insights and skills in stroke rehabilitation are taught in regular meetings and courses [32]. Inpatient and outpatient rehabilitation are offered at the rehabilitation stroke unit. Participants are prepared for their return home by means of a weekend leave. After care is provided after discharge by a nurse specialized in stroke rehabilitation for a maximum of two years with a minimum of three contact moments in the two-year period.

Data collection

This article presents findings from an in-depth study that was part of a larger qualitative research project on home- and place-making by stroke survivors with moderate to severe disability [7]. For the larger study, we conducted semi-structured interviews with stroke survivors about their needs, concerns and expectations during the rehabilitation, post-discharge, and reintegration phases in the rehabilitation process. Since participants frequently raised the issue of mobility, we decided to gain a deeper understanding of their mobility practices by performing a second qualitative analysis of the empirical material. Inspired by literature we extracted all texts on mobility from the transcripts, by focusing on mobility practices in clinical, family, work, and leisure life, as well as on the political dimension of mobility.

Semi-structured interviews with stroke survivors were carried out in the larger study by the first author (a movement scientist and physiotherapist) and two students from human geography. The interviews lasted between 45 minutes to 1.5 hours. All interviews were conducted at a location that was convenient for the participants, and a significant other was often present. A sample of twenty-four participants were interviewed once, in the reintegration phase between 6 months and 6.5 years, after the onset of the stroke. A sample of nine participants were interviewed twice. First, they were interviewed in the clinical phase during inpatient rehabilitation (between 1 and 4 months post-stroke). The second interview was conducted in the discharge phase, after being discharged from the rehabilitation stroke unit (between 2.5 and 10 months post-stroke). Overall, the interview guides covered the same questions. Participants were asked to reflect on their needs, concerns, expectations, and relations with meaningful places in the clinic and their pre-stroke and post-stroke current lives at

home and in the community. In the second interview session, they were also asked to recount their actual discharge experiences in an attempt to deal with the complicated issue of looking forward and backward to needs, concerns, and expectations. The interviews were digitally recorded and transcribed verbatim.

Data analysis

We applied our theoretical understanding of mobility as discussed in the section above, and focused our analysis on how stroke survivors embody and handle their (im)mobilities in everyday life [25,26]. The notion of embodied mobility as situated in different socio-spatial contexts directed our attention to human and non-human actors that enabled or disabled stroke survivors' mobilities at and between places. Our approach to the data-analysis was both deductive (secondary analysis) and inductive (primary analysis larger study) [33], which enhanced the depth of our analysis [34].

Coding and analysis were carried out separately by the first (physiotherapist and movement scientist) and second author (human geographer) with help of Atlas-ti, a software package for qualitative data analysis [35]. The emerging results were discussed with and reflected on by the last author (philosopher of science and medicine and physiotherapist). In case of disagreements, the authors discussed these matters until consensus was reached, often resulting in a specification of the analyses. Thus, inter-coder reliability was enhanced. Our interdisciplinary analytical work helped to articulate the specificities of the mobility practices of stroke survivors by unraveling and articulating them from more than one theoretical position. Thus, our focus was on theoretical triangulation rather than methodological triangulation [36].

Findings

Context in mobility practices

In this study, we focused on three contexts in which mobility practices are played out: the rehabilitation center, home and community [24–26]. We found that our participants' mobilities are enabled or disabled in everyday activities, both by physically and cognitive opportunities, and by human and non-human obstacles. During inpatient rehabilitation, most participants learned to move around fairly safely and independently in the clinic. When back home again, however, many reported having difficulties with this aspect in their own house. They said that the physical environment in the clinic was adapted to their needs, unlike the impediments at home. Staircases were a frequently cited example. John, for instance, explained that mobility training in the clinic had not really prepared him for the stairs he had to climb at home.

John: For example, we had practised on the stairs, but the stairs at Beatrixoord were very different from at home. They're not the same at all. It might have been easier if someone had come with me to practise at home, for safety reasons to see how it all went. Then you'd know what to do. Now I had to work it all out by myself, which I found very difficult in the beginning. It was also hard for my sons because they also didn't know what to do.

At home, John felt that he had to work out for himself how to go up and down stairs. Especially troubling was the fact that the stairs at the clinic were straight, whereas those at home turned a 90° corner. This meant that some steps were narrower on one side and difficult to negotiate, and John was afraid of falling when going downstairs. Home modifications, such as installing grab handles in this case, only solved part of the problem, since John still had to take the stairs. It was not only the physical

Table 1. Participant characteristics.

No ^a	Pseudo-nym	Age (years)	Stroke	Effects of stroke	Mobility aid	Mobility means ^b	Marital status/ children (living at home)	Moved ^c	Work status	Time of interview after stroke (months) ^d
1	John	57	Ischemic stroke left	Motor and cognitive problems	Cane	Mobility scooter	Single/2 (1)	Yes (a)	Incapacitated	5–6
2	Paul	50	Ischemic stroke left	Motor problems	None	Bike	Single/2	No	Working	16–17
3	Jim	66	Ischemic stroke left	Motor and behav- ioral problems	None	Electric bike, car	Married/2	No	Pensioner	16–17
4	Simon	41	Ischemic stroke left	Motor, behavioral and mood prob- lems, swallowing problems	Walker	None	Single/2	Yes (a)	Incapacitated	49–50
5	Mary	58	Ischemic stroke right	Motor, cognitive and mood problems	None	Bike, car	Single/-	Yes (b)	Working	33–34
6	Tom	60	Ischemic stroke right	Motor, cognitive and speech problems	None	None	Married/2	No	Incapacitated	44–45
7	Caren	60	Ischemic stroke right	Motor and cognitive problems	None	Bike, taxi	Single/-	No	Partly incapacitated	22–23
8	Sam	40	Hemorrhagic stroke right	Cognitive, mood, speech and sight problems, epilepsy	None	Bike	Cohabiting/1 (1)	No	Partly incapacitated, partly sickness benefit	22–23
9	Nina	47	Hemorrhagic stroke left	Motor, cognitive and sight problems	None	None	Married/2 (1)	No	Incapacitated	16–17
10	Violet	42	Hemorrhagic stroke left	Motor and cognitive problems	None	Bike, car	Cohabiting/2 (2)	No	Incapacitated	13–14
11	James	58	Ischemic stroke right	Cognitive and behavioral problems	None	Bike	Married/2 (2)	No	Sickness	5–6
12	Victor	71	Ischemic stroke left	Motor and speech problems	Walker	Electric bike, taxi	Married/2	No	Pensioner	19–20
13	Rose	53	Hemorrhagic stroke right	Motor and cognitive problems	None	Bike	Married/2 (2)	No	Incapacitated	31–32
14	Laura	49	Hemorrhagic stroke left	Motor and cognitive problems	Cane	None	Married/-	No	Sickness benefit	22–23
15	Steven	49	Ischemic stroke right	Motor and cognitive problems	None	None	Married/1 (1)	No	Sickness benefit	32–33
16	Ben	31	Ischemic stroke left	Motor and cognitive problems	None	Ladies bike, car	Cohabiting/-	Yes (a)	Unemployed	31–32
17	Marc	68	Ischemic stroke right	Motor and speech problems	None	Mobility scooter, car	Married/2	No	Pensioner	70–71
18	Daniel	81	Ischemic stroke left	Motor problems	Cane or walker	Taxi	Single/2	Yes (a)	Pensioner	41–42
19	Joan	64	Hemorrhagic stroke left	Motor and cognitive problems	Cane	Mobility scooter, shared taxi	Single/-	No (c)	Incapacitated	72–73
20	Sarah	67	Hemorrhagic stroke right	Motor, cognitive, behavioral and speech problems	Cane	Mobility scooter	Married/2	Yes (a)	Pensioner	55–56
21	Bob	63	Hemorrhagic stroke right	Cognitive and behavioral problems	None	Car	Married/1	No	Sickness benefit	32–33
22	Isa	48	Ischemic stroke right	Motor and cognitive problems	Walker	Mobility scooter	Single/-	Yes (a)	Incapacitated	77–78
23	Linda	72	Ischemic stroke right	Motor and behav- ioral problems	Walker	None	Single/2 (1)	No	Unemployed	59–60

(continued)

Table 1. Continued

No ^a	Pseudo-nym	Age (years)	Stroke	Effects of stroke	Mobility aid	Mobility means ^b	Marital status/ children (living at home)	Moved ^c	Work status	Time of interview after stroke (months) ^d
24	Mike	69	Ischemic stroke right	Motor and behav- ioral problems	None	Bike, shared taxi	Married/6	No	Pensioner	9–10
25 ^a	Kate	61	Ischemic stroke right	Motor problems	1) Walker 2) None	1) None 2) Bike	Married/5 (1)	No	Unemployed	1) 1–2 2) 7–8
26 ^a	Regina	55	Ischemic stroke right	Motor and cognitive problems	1) Quad cane 2) Cane	1) Wheelchair, taxi, mobility scooter 2) Shared taxi, wheelchair, work chair	Widow/2	Yes (a)	Unemployed	1) 3–4 2) 9–10
27 ^a	Henry	69	Ischemic stroke right	Motor problems	1) Walker 2) None	1) Three-wheeled bike 2) Bus	Married/1	No	Pensioner	1) 1–2 2) 4–5
28 ^a	Ron	63	Ischemic stroke right	Motor and cognitive problems	1) None 2) None	1) Bike 2) -	Married/-	No	Pensioner	1) 1–2 2) 2–3
29 ^a	Molly	46	Ischemic stroke left	Motor and cognitive problems	1) Cane 2) Cane	1) Wheelchair 2) Wheelchair, taxi	Married/1 (1)	No	Sickness benefit	1) 1–2 2) 3–4
30 ^a	Howard	51	Ischemic stroke left	Motor, cognitive, speech and sight problems	1) Walker 2) Walker	1) Mobility scooter 2) Taxi, mobility scooter	Long-distance rela- tionship/1	No	Unemployed	1) 2–3 2) 6–7
31 ^a	Roy	66	Ischemic stroke left	Cognitive problems	1) None 2) None	1) Bike 2) Bike	Single/-	No	Pensioner	1) 1–2 12) 5–6
32 ^a	Peter	46	Ischemic stroke left	Motor and behav- ioral problems	1) Elbow crutch 2) None	1) Wheelchair 2) Bike, public transport	Married/2 (2)	Yes (d)	Sickness benefit	1) 1–2 2) 5–6
33 ^a	Raymond	68	Ischemic stroke right	Motor problems	1) None 2) None	1) Wheelchair 2) -	Married/2	No	Pensioner	1) 1–2 2) 6–7

^aParticipants 25–33 were interviewed twice, once during the clinical phase, and once during the discharge phase.^bMobility means (participants 25–33): 1) Mobility means used in the clinical phase, 2) Mobility means used in the discharge phase.^cMoved: (a) to a ground-floor apartment, (b) to a house in a quiet city neighborhood, (c) to an assisted-living home, (d) to a terraced house in a city.^dTime of interview after stroke (participants 25–33): (1) Time of first interview (conducted in the clinical phase between 1 and 4 months post-stroke); (2) Time of second interview (conducted in the discharge phase between 2.5 and 10 months post-stroke).

environment (stairs, corner) that differed between home and the clinic, however. The social environment was also different. At the clinic, therapists taught John how to manage the stairs and they were always close at hand, whereas his sons were not always at home, and when there, did not know how to help their father take the stairs. Because of the uncertainties John experienced, he decided to move to a single-storey apartment.

Like John, many of our participants had difficulty applying the skills learned in a therapeutic environment to their own living environments. Mike developed various strategies for taking the stairs:

Mike: It takes so long because I have to take the stairs slowly and then there's no problem. And going down again, from upstairs to downstairs, on a good day I can walk down as well as anyone. But if I hear the doorbell and I have to go down quickly, I go down backwards, to be on the safe side.

Mike was able to adjust his pace and the way he tackled the stairs, depending on the situation, which shows considerable flexibility. It was not just the staircase, however; all his pre-stroke routines took a lot of time and energy. He therefore chose to move to a house with a downstairs bedroom so that he could free up time for more pleasant things than going up and down stairs.

When going outdoors, our participants faced more and different obstacles than inside the home. Typically, these obstacles were caused by their hemiplegic body. There were also cognitive problems when dealing with busy situations. Rose told us how the physical environment outdoors did not accommodate her hemiplegic body:

Rose: I just don't feel confident when I walk. The paving stones are hopeless, you soon discover that if you can't walk properly, all paved paths are crooked. That means that I go out less often than I could.

Because footpaths differed from the even paths at the rehabilitation clinic, Rose went outdoors less often than she would have liked after returning home. Ben explained that although he did go out, he sometimes struggled if something unexpected happened, such as having to go to the second floor of a shop without a lift.

Ben: Well, in shops with a lift, I take the lift. Because people are used to walking on the right-hand side of the stairs. I can use my right hand, but it drags a lot. So I really have to try and get my arm up onto the railing and raise my leg as well, which is very difficult. I should really walk on the left if I take the stairs.

Ben, who suffered from a right-sided hemiplegia, took the left side of the stairs because that gave him more support for his body. However, that meant having to move against the traffic flow, as people in the Netherlands keep to the right. Therefore, although most shop staircases are wide and therefore resemble staircases in rehabilitation clinics, they are not used solely by rehabilitation professionals and peers, but by people who are unaware of the special needs of hemiplegics.

Similarly, other participants' stories show that post-stroke bodies are often not acknowledged and accommodated in public spaces, in both social and physical respects. Sarah, for instance, would avoid crowded places or ask her husband to accompany her.

Sarah: Then I go out onto the street with my husband because I've fallen over a few times ... Busy places and such, people push against you and don't watch where they're going. I tend to avoid it, escalators and that sort of thing ... In my case, my husband also needs to feel like going out with me.

Because Sarah was afraid of falling in public, she became dependent on her husband's support. The above stories demonstrate the challenges involved in moving around in the outdoor

physical and social environment. Many of our participants avoided public places, or when they had to go out, they planned carefully how, when and with whom they would go. We found that it is more difficult for stroke survivors to achieve satisfactory ambulation in public than in private spaces, and more difficult in private than in clinical spaces. This indicates that stroke survivors should not just comply with lessons that professionals set out for them in the clinic. Rather they should be supported in coordinating, transforming, dismissing, and attuning the taught lessons to ever changing socio-spatial contexts outside the clinic.

Ambivalences in mobility practices

Mobility is important for balancing work, family life, in leisure and pleasure [20]. We describe the ambivalences that our participants experienced in their attempts to be mobile at home and in the community in their post-stroke lives. John, for instance, told us how he juggled to maintain his mobility after his discharge from the clinic:

John: I've actually gone backwards because I move a lot less now, only when I have to. The therapy (at Beatrixoord) was like a big stick to keep me moving. I only go outside occasionally now. ... I can't get to the shops because I would have to walk and it's too far, it's 500 metres I think. I'm still getting a mobility scooter and a serving trolley, I've applied for them. But it'll take ages before I get them ... Everything depends on my son, who still lives at home. I don't get any household help, because he still lives at home and he also has to do the grocery shopping. That's really difficult because he's away from home for 12 hours and has to do it all in the evening.

There are several ambivalences in John's story. First, he wanted to go outdoors in order to maintain his walking ability, but when outdoors he was unable to participate in valued activities, such as walking to the shop. This clashed with his wish to engage in useful activities and to give his son some relief from the triple burden of work, household and care activities. John did get a mobility scooter in the end, which enabled him to engage in activities such as grocery shopping, thereby improving his family and community life. At the same time, however, his frequent use of the mobility scooter meant that he walked even less, which led to a further deterioration in his physical condition. The major ambivalence that is played out in John's case is how family and societal roles were served by a mobility scooter, which at the same time worked against his physical fitness, a clinically significant factor. Similar ambivalences surfaced in the stories of other participants.

As well as physical impairments, our participants also talked about cognitive impairments that limited their community mobility. Mary, for instance, had become hypersensitive to stimuli after her stroke. Mary was single and had a busy working and social life pre-stroke. However, cognitive impairments and fatigue meant that she could not continue all these activities. Mary chose to continue to work, but that meant she had to quit activities such as regular visits to friends and going to the fitness center. She also had to plan almost all her activities in advance, such as shopping.

Mary: When I go shopping I always prepare a shopping list the day before. I know exactly where everything is in the shop. So I write my list based on the route I take through the shop. ... And so I arrive, grab a trolley, go into the shop and don't even have to think about it. I grab what's on the list, pay and leave. I never think "Oh, that's on special" or "hey, what's that?" No, that's what I need, I grab it and in it goes. Then I'm happy to be able to go home, ha ha.

For Mary, shopping had become a planned, controlled trip. She could no longer take the time to compare different products and get the best deals available, as that took too much of her energy. As well as working and grocery shopping, Mary continued cycling

as a leisure activity, although it had become demanding for her post-stroke. She had to think consciously about every push on the pedals to prevent herself from falling. Despite this, she developed strategies that enabled her to enjoy cycling again:

Mary: I don't take the time to look around and think, hey this is lovely ... No, you think gosh I'm tired or I have to sit for a bit. ... Then I find a bench and I go and sit down. I always have a book with me or a puzzle book you know, or a bottle of water, I always carry all those things with me. ... It keeps me happy for a whole afternoon.

Cycling used to be a leisure activity in which Mary could enjoy both the physical activity and the scenery along the way. Post-stroke, however, she had to plan it in advance, including creating opportunities for rest, during which she could look at the scenery. The ambivalence in Mary's story comes from the time and effort she now needed for work, shopping and cycling. As a result, she had very little time and energy to engage in other activities that were valuable to her, such as meeting friends, going to the fitness center and shopping for pleasure.

The quotes from Mary and the other participants show how stroke survivors have to be creative in dealing with the ambivalences and tensions they face in regaining mobility in home and community life. It is this process of endless tinkering, weighing, adjusting, and coordinating mobility practices in each situation anew, that needs to be acknowledged by the rehabilitation team [22]. Indeed, at home everything hangs together, whereas different aspects of post-stroke life are allocated to different team members in the clinic pre-discharge. After discharge, stroke survivors and their families need to figure out how to set priorities in their mobility practices, to achieve satisfactory bodily, family, working, and community lives, to let go of particular pre-stroke pleasures, and to reformulate goals every day and everywhere, every time and again.

The politics of mobility practices

Our third findings-section outlines the inequalities in access to resources, such as personal abilities, a social network and money, between the participants. This underlines the political dimension of mobility [24,26]. Participants experienced differences in accessing health care in general, and obtaining mobility aids in particular. Their stories revealed that it is in fact difficult to arrange mobility aids such as grab bars along the stairs, braces, walkers, wheelchairs, mobility scooters and taxi transport. Many participants felt that they had to work out by themselves what aids they needed, and how to get them. Take, for example, the story of Tom's partner, who explained how they discovered that the mobility aids recommended by professionals at the rehabilitation center – in their case a mobility scooter and wheelchair for community ambulation – did not work well for them at home, and how they struggled to get the right aids.

Tom's partner: So, you're discharged home, and you're asked what would you need at home, what kind of aids, what kind of support, but at that moment, you have no idea yet. Only when you're at home does it become clear what you need, or what's missing, only then is it possible to say. [...] So we needed to change stuff. We got the mobility scooter, we got the wheelchair. But then I asked for a disability parking permit. "Well," she said, "we don't need to apply for that, you'll never get it, it's very difficult". But now, it's what we enjoy most. I put a lot of effort into getting the permit, because you're not allowed to park anywhere these days, and he couldn't walk that far, so I didn't go anywhere. [...] So we gave back the wheelchair and bought a smaller mobility scooter.

Although Tom did not use his large mobility scooter for months, they had to pay for it every month. And the wheelchair

did not work out in practice because Tom's wife, who was much lighter than Tom, had to push it. She would quickly become exhausted, especially on difficult surfaces. Both Tom and his wife found the small mobility scooter and the parking permit ideal for their community mobility.

However, many of our participants did not have the capabilities or support of family members to select and negotiate the aids and facilities that are available from municipalities but are difficult to acquire, such as a disability parking permit. Their mobility at home and in the community remained limited. In particular, the fragmented organization of health care and related provisions was seen as an almost insurmountable obstacle to extending their mobility range and with that, their social participation. Steven's partner explained how she felt burdened by this fragmentation as an informal carer:

Steven's partner: You just have to apply for everything yourself, all that paperwork, it's enough to drive you crazy. Those appointments, you have to make the time for it all. He has to go in a wheelchair, in a shared taxi, he needs to have grab bars, he needs such and such. And every appointment is something different. So a grab bar is something different from a modification for the shower, which is different again from another appointment with the council and the share taxi that you need. And that's different again from having the back of the house modified. Yes, you can't keep dividing yourself up and working thirty hours and everything ... And another year has just flown by.

The fragmentation Steven's partner told us about is caused at least in part by the fact that in the Dutch health care system, different organizations are responsible for different aids and facilities, and there is a lot of administration involved. Stroke survivors and their families have to make separate appointments and arrangements for mobility aids, home adaptations and transport provision. Stroke survivors and caregivers explained that schemes are often not clear and differ from one municipality to the next. This seems to give stroke survivors and their spouses unequal access to resources, which also indirectly restricts their community mobility. As a result, some participants were unable to arrange the mobility aids and facilities they needed in their own living environment, or it took a long time to do so. For example, not all our participants had the resources to get their driving license back or the financial resources to maintain a car. Take Isa, for example, whose social life was hugely affected:

Isa: You do lose quite a few friends because you can't do everything independently any more. I always used to drive myself – I went everywhere. I couldn't do that now. And now I'm allowed to drive again, but I can't afford a car anymore because I've been incapacitated.

Although Isa eventually regained her driving license, she could no longer afford a car. The stroke had left her unable to work, which limited her financial resources. Like Isa, many of our working-age participants became unfit for work post-stroke, and received a sickness benefit that was less than the income they had earned when working. This illustrates that participants with better financial resources and pre-stroke working conditions appear to be less home-bound. This section has shown that the political aspect of mobility, in terms of having unequal access to resources, influences the number of outings and activities of stroke survivors and their families. Moreover, the bureaucratic logic survivors and their families are facing post-discharge, complicates the tinkering process that has been articulated in the previous two sections. Such findings would have been easily overlooked when framing mobility as a movement from A to B, or in effectiveness research that isolates a few variables to be able to account them.

Discussion

Inspired by the mobility turn in the social sciences [24–27], we analyzed post-stroke mobility as embodied by survivors and their families in real-life practice. In our in-depth study, we conceptualized mobility as a set of materially heterogeneous practices rather than as an individual's ability to move from A to B. This revealed our participants' mobility in its full complexity.

The first complexity that emerged was that stroke survivors' mobility differs from one context to the next. Our participants' stories showed that moving around in public and private spaces safely, easily and independently involves more than simply being physically able to walk without the help of others and assistive devices in an otherwise rather empty space with an even floor, such as the rehabilitation clinic gym. Instead, it involves dealing with different human actors (such as children, partners, and passengers in public space) and non-human actors (such as staircase winders, bars, doorbells and traffic rules), which interact differently in a range of contexts. The problems survivors face in the private context of home may eventually be manageable because the home environment is relatively easy to control, through creative strategies, practical home adaptations and the family adjusting to the stroke survivors' physical and cognitive impairments. Public space, however, is much more difficult to control as it involves greater complexity. It is extremely difficult for stroke survivors to navigate through public spaces in both a physical and social sense [9]. People in public spaces are barely aware of the problems stroke survivors face and therefore do not take them into account, unlike in clinical and private spaces. Because moving around in different contexts involves dealing with different interacting human and non-human actors, stroke survivors have to learn and negotiate their mobility anew in each context. This is extremely fatiguing and may play a part in fatigue as a unique post-stroke condition rather than add to tiredness as an ordinary life event [37,38].

The second complexity that emerged was that the mobility of stroke survivors is full of ambivalences and shifting tensions. They have to do a lot of tinkering to balance exercise and training, family and working life, and leisure and pleasure [22]. To improve social participation in the mobility domain we need to regard stroke survivors as people who are both attached and detached, independent and dependent, moving on their own and being moved by others [39]. Our study demonstrates that stroke survivors find their way between these opposing states by making small alterations and adjustments to their socio-spatial environments where they want or need to be, such as taking the stairs at the shopping mall against the flow of the crowd in the absence of a lift, relying on a mobility scooter to provide some relief for family caregivers, making an efficient shopping list as a guide for the route taken through the supermarket in order to save time and energy, and planning a cycling trip that incorporates rest stops at benches along the way. This corresponds to the core category of "striving to manage an everyday life of uncertainty" in Carlsson et al.'s [40] study.

The third complexity is that mobility is impacted by the different resources that stroke survivors have in terms of income, pre-stroke working conditions, health literacy skills and social support. The bureaucratic logic and fragmentation of the Dutch health care system in general, and the different municipal arrangements in particular, can mean a never-ending story of applying for mobility aids and driving licenses, transport compensations, house modifications and so on. Stroke survivors with cognitive impairments have difficulty dealing with these complex administrative matters, which means that their partners or other family members

have to do it all, which in turn places a heavy burden on them. As a result, both stroke survivors and their partners are at risk of becoming socially isolated or burnt out [40–43]. We therefore argue that this burden should not be placed on the shoulders of stroke survivors and their spouses alone, with individuals expected to take more responsibility for their own health. Instead, it should be seen as a collective task, as shared work to reduce the burden for stroke survivors and their family caregivers [44–46]. The political dimension of access to healthcare in general has also been described as highly dynamic, multi-dimensional and contingent character in minority group research [47]. In their critical interpretive study of the literature Dixon-Woods and associates [47] describe transport as a key practical resource that impacts on the ability to seek care for the socio-economically disadvantaged. Also, financial costs and lack of awareness of certain services act as a barrier to attending "optional" services related to health promotion and health prevention [47].

As in all research, there are several limitations to our study. One limitation is that we conducted a secondary analysis of empirical material that had been collected for a different purpose originally [7]. Therefore, saturation - in the sense that researcher reaches a point in the analysis that sampling of more data will not lead to more information related to the research questions, is a matter of concern. However, the value of saturation, beyond grounded theory, is under debate [48], and may not apply to our study, since the aim of our study was not to develop theory that is grounded in data systematically gathered and analyzed. Rather, we aimed to extract practical, sometimes silenced, knowledge of stroke survivors that may be useful for peers, practitioners, and researchers [21]. Our interdisciplinary analytical approach did have an added value with respect to that aim. Indeed, triangulation is not just about methodological validation, but also about theoretical triangulation aimed at deepening and explaining more fully the richness and complexity of human behavior from more than one theoretical perspective, in this case stroke patients' (im)mobilities from the perspectives of rehabilitation medicine, human geography, and philosophy of science and medicine [36].

A second limitation is that we did not observe our participants' mobility practices, but took the stories about their (im)mobilities in everyday life as object of analysis. To enhance methodological triangulation, we recommend conducting "go-along" interviews [48,49] with stroke survivors in future research. These will facilitate observation of mobility practices with reflective questioning [50]. The advantage of go-along interviews as a research method is that it may help to turn the articulated patient knowledge into ethnographic science [21]. In this emerging field of research, knowledge is not about facts and truths, but a tool in improving rehabilitation care [22]. As such it shifts focus away from proving to improving care practices, and makes it transferable and useful for others [21,51].

In spite of our study's limitations, the complexities we uncovered suggest that there needs to be a critical review of the current focus by rehabilitation practitioners and researchers on adherence to mobility and exercise training at home [12–14,16]. These scholars seem to implicitly assume that an effective exercise program at a fitness center or at home is the best way to sustain or improve mobility after inpatient rehabilitation. Rimmer et al. [12], for example, identified five common barriers to exercise adherence: the cost of the program, not knowing about a fitness center in the vicinity, no way of getting to the fitness center, and no knowledge of how and where to exercise. Similarly, van de Port et al. [11] suggest in their prognostic study that intensive physical training aimed at improving the walking competence of chronic stroke patients, combined with pharmacological treatment, will increase mobility

and reduce the risk factors of fatigue and depression. Contrary to these studies, our findings indicate that sustaining or improving physical activity and related ambulation in home and community settings can only be explored in these varied settings themselves, and should not be controlled or introduced from the outside in a general way or in accordance with general physiological and pharmacological principles. Rather, in rehabilitation medicine, community participation, ambulation and mobility should be seen as a personal goal, and dealt with in the context of the complexities inherent in home, working and community life in private and public spaces outside the clinic.

Our findings thus underline that outcome measurements developed for the clinic such as the 10-meter walk test, independence and fatigue scales [52–55] may be inadequate for evaluating participation in the mobility domain [5]. Such measurements do not capture the multiplicities inherent in real-life settings and therefore say little about how mobility or home and community ambulation occurs outside the clinic. That is why it would be useful for future research to objectify individual stroke survivors' favorite places in the community in terms of how often they go there and whether or not they extend their mobility range, during their life course or after an intervention. This could be achieved through GPS technology, which has been used in other fields of health research [56].

The complexities in mobility practices that we uncovered in this article call for the support of professionals who are aware of the many aspects of community mobility after a stroke and the multiple ways these interact with each other when survivors return home and thereafter. This is important because in clinical terms different aspects of mobility and alternative forms of transport tend to be viewed as separate disciplinary domains, rather than as fluid and interconnected. For example, the rehabilitation unit under study assigned gait and bike training, including adaptations, to the domain of physiotherapists, home adaptations, wheelchair and mobility scooter provisions and related administrative matters to the domain of occupational therapists, and spouse problems and administrative matters to that of social workers. Therefore, we are currently working on an intervention in which a multi-problem coach has a key-role in helping stroke survivors and family caregivers to take up their lives again in their everyday environment.

The idea of the multi-problem coach has been conceptualized in co-creation with researchers, rehabilitation practitioners and stroke survivors, including family caregivers. The theoretical foundations of the intervention can be traced to concepts of home-making, place attachment and place identity that have been developed in human geography and environmental psychology [7], as well as on knowledge from migrant, transport and science studies [24,26,31,39]. By combining coaching at home (face-to-face contact) and over distance (screen-to-screen application), and by developing an assessment tool that focuses on the altered (place) identity of stroke survivors, we aim to support the home-making process and mobility of stroke survivors in places they wish or need to be. In this way, we hope to help bring about change in the way that care for community-dwelling stroke survivors and their spouses is thought about, implemented and organized, and thereby to narrow the gap between clinical and home settings. We hope that others will join us.

Acknowledgements

Special thanks go to the individuals who took part in this study. We would also like to thank Linden Douma and Jelle Straatsma,

Master's students at the Faculty of Spatial Sciences, University of Groningen for their contribution to this study.

Disclosure statement

The authors report no conflicts of interest.

References

- [1] Craig LE, Wu O, Bernhardt J, et al. Predictors of poststroke mobility: systematic review. *Int J Stroke*. 2011;6:321–327.
- [2] Intercollegiate Stroke Working Party: National Clinical Guideline for Stroke. 4th ed. London: Royal College of Physicians; 2012.
- [3] World Health Organization. International Classification of Functioning, Disability and Health (ICF). Geneva: World Health Organization; 2001.
- [4] Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. *Lancet*. 2011;377:1693–1702.
- [5] Lord SE, Rochester L. Measurement of community ambulation after stroke: current status and future developments. *Stroke*. 2005;36:1457–1461.
- [6] Robinson CA, Matsuda PN, Ciol MA, et al. Participation in community walking following stroke: the influence of self-perceived environmental barriers. *Phys Ther*. 2013;93:620–627.
- [7] Nanninga CS, Meijering L, Schönherr MC, et al. Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine. *Disabil Rehabil*. 2015;37:1125–1134.
- [8] Logan PA, Armstrong S, Avery TJ, et al. Rehabilitation aimed at improving outdoor mobility for people after stroke: a multicentre randomised controlled study (the Getting out of the House Study). *Health Technol Assess*. 2014;18:vii–viii.
- [9] Gardner P. The role of social engagement and identity in community mobility among older adults aging in place. *Disabil Rehabil*. 2014;36:1249–1257.
- [10] Lord SE, McPherson K, McNaughton HK, et al. Community ambulation after stroke: how important and obtainable is it and what measures appear predictive? *Arch Phys Med Rehabil*. 2004;85:234–239.
- [11] van de Port IG, Kwakkel G, van Wijk I, et al. Susceptibility to deterioration of mobility long-term after stroke: a prospective cohort study. *Stroke*. 2006;37:167–171.
- [12] Rimmer JH, Wang E, Smith D. Barriers associated with exercise and community access for individuals with stroke. *J Rehabil Res Dev*. 2008;45:315–322.
- [13] Simpson LA, Eng JJ, Tawashy AE. Exercise perceptions among people with stroke: barriers and facilitators to participation. *Int J Therapy Rehab*. 2011;18:520–530.
- [14] Gordon NF, Gulianick M, Costa F, et al. Physical activity and exercise recommendations for stroke survivors: an American Heart Association scientific statement from the Council on Clinical Cardiology, Subcommittee on Exercise, Cardiac Rehabilitation, and Prevention; the Council on Cardiovascular Nursing; the Council on Nutrition, Physical Activity, and Metabolism; and the Stroke Council. *Circulation*. 2004;109:2031–2041.
- [15] Yong V. Mobility limitations. In: JH Stone, M Blouin, editors. *International Encyclopedia of Rehabilitation*. New York (USA): the Center for International Rehabilitation Research

- Information and Exchange (CIRRIE); 2010. Available from: <http://cirrie.buffalo.edu/encyclopedia/en/article/259/>.
- [16] Pollock A, Baer G, Campbell P, et al. Physical rehabilitation approaches for the recovery of function and mobility following stroke. *Cochrane Database Syst Rev*. 2014;22:CD001920.
- [17] Barclay RE, Stevenson TJ, Poluha W, et al. Interventions for improving community ambulation in individuals with stroke. *Cochrane Database Syst Rev*. 2015;13:CD010200.
- [18] Stretton CM, Mudge S, Kayes NM, et al. Interventions to improve real-world walking after stroke: a systematic review and meta-analysis. *Clin Rehabil*. 2016;31:310–318.
- [19] Robinson CA, Shumway-Cook A, Ciol MA, et al. Participation in community walking following stroke: subjective versus objective measures and the impact of personal factors. *Phys Ther*. 2011;91:1865–1876.
- [20] Elbers RG, Rietberg MB, van Wegen EE, et al. Self-report fatigue questionnaires in multiple sclerosis, Parkinson's disease and stroke: a systematic review of measurement properties. *Qual Life Res*. 2012;21:925–944.
- [21] Pols J. Knowing patients: turning patient knowledge into science. *Sci Technol Human Values*. 2014;39:73–97.
- [22] Mol A, Moser I, Pols J, editors. *Care in practice: on tinkering in clinics, homes and farms*. Bielefeld: Verlag; 2010.
- [23] Mol A. *The logic of care. Health and the problem of patient choice*. London: Routledge; 2008.
- [24] Sheller M, Urry J. The new mobilities paradigm. *Environ Plan A*. 2006;38:207–226.
- [25] Cresswell T. Mobilities I: catching up. *Prog Hum Geogr*. 2011;35:550–558.
- [26] Cresswell T. Mobilities II: still. *Prog Hum Geogr*. 2012;36:645–653.
- [27] Ziegler F, Schwanen T. 'I like to go out to be energised by different people': an exploratory analysis of mobility and well-being in later life. *Ageing Soc*. 2011;31:758–781.
- [28] Schwanen T, Ziegler F. Wellbeing, independence and mobility: an introduction. *Ageing Soc*. 2011;31:719–733.
- [29] Schwanen T, Hardill I, Lucas S. Spatialities of ageing: the co-construction and co-evolution of old age and space. *Geoforum*. 2012;43:1291–1295.
- [30] Gregory D, Johnston R, Pratt G, et al. *The dictionary of human geography*. 5th ed. Oxford: Wiley-Blackwell; 2009.
- [31] Struhkamp R, Mol A, Swierstra T. Dealing with in/dependence: doctoring in physical rehabilitation practice. *Sci Technol Human Values*. 2009;34:55–76.
- [32] Stroke Unit Trialists' Collaboration. Organized inpatient (stroke unit) care for stroke. *Cochrane Database Syst Rev*. 2013;9:CD000197.
- [33] Hennink M, Hutter I, Bailey A. *Qualitative research methods*. London, United Kingdom: Sage Publications; 2011.
- [34] Thornberg R. Informed grounded theory. *Scand J Educ Res*. 2012;56:243–259.
- [35] Muhr T, Friese S. *User's Manual for Atlas.ti 5.0*. 2nd ed. Berlin, Germany: Scientific Software Development; 2004.
- [36] Walsch K. When I say ... triangulation. *Med Educ*. 2013;47:866.
- [37] Kirkevold M, Christensen D, Andersen G, et al. Fatigue after stroke: manifestations and strategies. *Disabil Rehabil*. 2012;34:665–670.
- [38] Flinn NA, Stube JE. Post-stroke fatigue: qualitative study of three focus groups. *Occup Ther Int*. 2010;17:81–91.
- [39] Winance M. Care and disability. Practices of experimenting, tinkering with, and arranging people and technical aids. In: *Care in practice: on tinkering in clinics, homes and farms*. Bielefeld: Verlag; 2010. p. 93–117.
- [40] Carlsson GE, Möller A, Blomstrand C. Managing an everyday life of uncertainty – a qualitative study of coping in persons with mild stroke. *Disabil Rehabil*. 2009;31:773–782.
- [41] Haley WE, Roth DL, Kissela B, et al. Quality of life after stroke: a prospective longitudinal study. *Qual Life Res*. 2011;20:799–806.
- [42] Salter K, Hellings C, Foley N, et al. The experience of living with stroke: a qualitative meta-synthesis. *J Rehabil Med*. 2008;40:595–602.
- [43] Andrew NE, Kilkenny MF, Naylor R, et al. The relationship between caregiver impacts and the unmet needs of survivors of stroke. *Patient Prefer Adherence*. 2015;9:1065–1073.
- [44] Greenwood N, Mackenzie A. Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas*. 2010;66:268–276.
- [45] Gallacher K, Morrison D, Jani B, et al. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS Med*. 2013;10:e1001473.
- [46] Van Heugten C, Visser-Meily A, Post M, et al. Care for carers of stroke patients: evidence-based clinical practice guidelines. *J Rehabil Med*. 2006;38:153–158.
- [47] Dixon-Woods M, Cavers D, Agarwal S, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol*. 2006;6:35.
- [48] O'Reilly M, Parker N. "Unsatisfactory saturation": a critical exploration of the notion of saturated sample sizes in qualitative research. *Qual Res*. 2013;13:190–197.
- [49] Carpiano RM. Come take a walk with me: the 'go-along' interview as a novel method for studying the implications of place for health and well-being. *Health Place*. 2009;15:263–272.
- [50] Lager D, Hoven BV, Huigen PPP. Understanding older adults' social capital in place: obstacles to and opportunities for social contacts in the neighbourhood. *Geoforum*. 2015;59:87–97.
- [51] Evans J, Jones P. The walking interview: methodology, mobility and place. *Appl Geogr*. 2011;31:849–858.
- [52] Mol A. Proving or improving: on health care research as a form of self-reflection. *Qual Health Res*. 2006;16:405–414.
- [53] Chitralakshimi K, Balasubramanian CK, Clark DJ, et al. Walking adaptability after a stroke and its assessment in clinical settings. *Stroke Res Treat*. 2014;2014:591013.
- [54] Rand D, Eng JJ, Tang PF, et al. How active are people with stroke?: use of accelerometers to assess physical activity. *Stroke*. 2009;40:163–168.
- [55] Eng JJ, Chu KS, Dawson AS, et al. Functional walk tests in individuals with stroke: relation to perceived exertion and myocardial exertion. *Stroke*. 2002;33:756–761.
- [56] Hirsch JA, Winters M, Clarke P, et al. Generating GPS activity spaces that shed light upon the mobility habits of older adults: a descriptive analysis. *Int J Health Geogr*. 2014;13:1–14.